DEPARTMENT OF HUMAN SERVICES

DIVISION OF DEVELOPMENTAL DISABILITIES

Decision-Making for the Terminally Ill

Proposed New Rules: N.J.A.C. 10:48B

Authorized By: Gwendolyn L. Harris, Commissioner,
Department of Human Services

Authority: N.J.S.A. 26:2H-53 et seq. and 26:6A-1 et seq.

Calendar Reference: See Summary below for explanation of exception to calendar requirement

Proposal Number: PRN 2002 - 450

Submit comments by February 14, 2003 to:

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The agency proposal follows:

Summary

Continuing advancements in medical technology have made possible the prolongation of the basic life functions of terminally ill individuals. These individuals may be in an irreversible coma, in a persistent vegetative state, or experiencing extreme physical and/or psychological pain and suffering. These situations have created profound moral dilemmas and legal issues as to decision-making with respect to the continuation or discontinuation of medical treatment. When individuals with developmental disabilities become terminally ill,

medical decision-making can become more difficult as the majority of these individuals have never had the capacity to make personal decisions on their own behalf.

The Department recognizes the need to establish guidelines to allow for responsible decision-making by or on behalf of terminally ill individuals with developmental disabilities. These guidelines specifically address issues regarding the continuation or cessation of life sustaining medical treatment. These would include instances when the individual is considered to have the capacity to make decisions for himself or herself, when a private guardian or family member is available to make surrogate decisions on behalf of an individual deemed to lack such capacity or when the Division of Developmental Disabilities, Bureau of Guardianship Services, is providing guardianship.

The two broad areas of decision-making, which are not mutually exclusive, involve whether or not to consent to a Do Not Resuscitate Order and the question of withholding or withdrawing life sustaining medical treatment.

Following is a summary of the provisions of each subchapter:

Subchapter 1 contains an introduction providing general guidelines regarding issues which need to be considered with respect to the provision of medical care to terminally ill individuals, and in particular those with developmental disabilities. It delineates the ethical dilemmas created as to the continuation or cessation of life sustaining medical treatment and also addresses the importance of palliative care to terminally ill individuals.

Subchapter 2 consists of the definitions of the terms to be used within the context of these rules.

Subchapter 3 addresses the designation of Ethics Committees by the Division Director.

Subchapter 4 contains guidelines and procedures relating to determining the capacity of the terminally ill individual to make medical decisions.

Subchapter 5 provides that individuals with developmental disabilities who have been determined by the attending physician to have the capacity to make medical decisions should do so on their own behalf.

Subchapter 6 delineates procedures to be followed when a terminally ill patient who lacks capacity to make medical decisions is not receiving guardianship services from the Bureau of Guardianship Services.

Subchapter 7 provides procedures to be followed when a recommendation is made by the attending physician to execute a Do Not Resuscitate Order or to withhold or withdraw life sustaining medical treatment for an individual receiving guardianship from the Bureau of Guardianship Services. It elaborates the role and functions of Ethics Committees as

consultative bodies when questions arise regarding the provision of medical treatment to terminally ill individuals receiving guardianship from the Bureau of Guardianship Services.

Subchapter 8 addresses the need for palliative care for terminally ill individuals, one form of which could be provided in a hospice program.

Social Impact

Society has an interest in ensuring the soundness of health care decision making, including both protecting vulnerable individuals from potential abuse or neglect and facilitating the exercise of informed and voluntary individual choice. The issue of providing medical intervention to terminally ill individuals with developmental disabilities has created a dilemma for decision-makers.

Terminally ill individuals with developmental disabilities should receive the highest quality of end-of-life care. The proposed new rules help to assure a system of checks and balances when decision-makers are faced with making end-of-life decisions.

The proposed new rules set forth the role of the Division when the Bureau of Guardianship Services is providing guardianship to a terminally ill individual with developmental disabilities.

The proposed new rules emphasize the need for the Division to provide a framework for the provision of palliative care. Palliative care encompasses the provision of appropriate

medical, emotional, physical, psychosocial and spiritual support and care of the terminally ill individual with developmental disabilities.

Economic Impact

The Division may need to bear some costs related to the provision of palliative care for individuals who are terminally ill and living in a facility or community home supported by the Division. Good end-of-life care for terminally ill individuals often requires the administration of care in a setting familiar to the individual. This contributes to the emotional and psychological well being of the individual. Accordingly, the Division will seek to create a framework so that, whenever appropriate, palliative care shall be available to terminally ill individuals within developmental centers and community residences in New Jersey. The Division will strive to use the resources for palliative care afforded to all other citizens. If the services are not available due to geographic considerations or funding issues, the Division will supply the resources to provide palliative care to a terminally ill individual who is receiving services from the Division.

Federal Standards Statement

The proposed new rules governing decision-making for the terminally ill contain requirements that do not exceed those imposed by Federal law or regulation. The proposed new rules are in compliance with the New Jersey Advance Directives for Health Care Act (N.J.S.A. 26:2H-53 et seq.), the Federal Individual Self-determination Act (42 U.S.C. §1395 cc), and the New Jersey Declaration of Death Act (N.J.S.A. 26:6A-1 et seq.).

The Department has reviewed the applicable Federal statute, the Federal Individual Self-determination Act (42 U.S.C. §1395 cc), and has determined that the proposed new rules do not exceed Federal requirements.

Jobs Impact

The proposed new rules governing decision making for the terminally ill will not generate jobs or cause any jobs to be lost.

Agriculture Industry Impact

The proposed new rules will have no impact on agriculture in the State of New Jersey.

Regulatory Flexibility Statement

A regulatory flexibility analysis is not required because the proposed new rules do not impose reporting, recordkeeping or other compliance requirements upon small businesses, as defined under the Regulatory Flexibility Act, N.J.S.A. 52:14B-16 et seq. Since the proposed new rules apply only to individuals served by the Division, they will not have any effect on small businesses or private industry in general.

Smart Growth Impact

The Department anticipates that the proposed new rules will have no impact on smart growth in New Jersey or in the implementation of the New Jersey State Development and Redevelopment Plan.

Full text of the proposed new rules follows:

CHAPTER 48B

DECISION-MAKING FOR THE TERMINALLY ILL

SUBCHAPTER 1. GENERAL PRINCIPLES

10:48-1.1 General Principles

(a) Staff of the Division shall be guided by the following principles with respect to decision-making for the terminally ill:

1. Concerning ethical issues:

i. The provision of appropriate end-of-life treatment for terminally ill individuals with developmental disabilities can raise some special ethical concerns. This is particularly the case for individuals with developmental disabilities who are receiving services from the State of New Jersey. On the one hand, the State has a special responsibility to protect individuals with developmental disabilities from all forms of discrimination, including medical treatment discrimination, based solely on the presence of a developmental disability. On the other hand, individuals with developmental disabilities who are terminally ill should not be subjected to medical interventions at the end-of-life simply because the State wishes to avoid the appearance of discrimination, that is, a perception that medical interventions are being withheld solely because of a individual's disabilities.

ii. In addressing the issue of providing medical interventions at the end of life for individuals who are terminally ill, medical ethics in the United

States has traditionally sought to find a middle ground between "medical pessimism," which withholds or withdraws treatment at the first signs of terminal illness, and "medical vitalism," which continues to provide treatments, however burdensome, until death occurs. Medical ethics has also created a framework for weighing the ethical obligation to provide interventions vs. the ethical decision to withhold and/or withdraw medical interventions. This framework identifies five major elements:

(1) The usefulness of treatment;

(2) The benefit of the treatment;

(3) The burden of the treatment;

(4) The ratio of benefit to burden; and

(5) An understanding of the wishes, values and goals of the individual and/or surrogate.

iii. To the extent possible, individuals with developmental disabilities who are receiving services from the State of New Jersey should receive the highest quality end-of-life care. Individuals acting on their behalf should seek to weigh the benefits and burdens of treatment in considering the best interest of the individual, that is, they should strive to avoid the moral wrong of under-treatment, as well as the wrong of over-treatment at the end of life. Finally, in all instances, they should make

every effort to protect and nourish the dignity of individuals with developmental disabilities confronting terminal illnesses.

2. Concerning palliative care:

   i. Individuals with developmental disabilities who are terminally ill should have access to the highest quality of palliative care. Palliative care encompasses a comprehensive approach to meeting the multi-dimensional needs of terminally ill individuals. It includes the provision of the appropriate medical, emotional, physical, psychosocial and spiritual support and care for the terminally ill individual.

   ii. A special dimension of a palliative care program is the provision of appropriate medications and therapies designed to alleviate the pain and suffering of the terminally ill individual. The provision of appropriate pain management for individuals with developmental disabilities who are terminally ill presents some special challenges because often the individual may be unable to adequately express the nature and locus of pain and suffering. Therefore, particular attention needs to be paid to this aspect of end-of-life care by health care professionals who are trained to meet this need.

   iii. In some instances, individuals with developmental disabilities who are terminally ill may benefit from a hospice program capable of providing

comprehensive end-of-life care. Terminally ill individuals should have access to hospice care whenever appropriate. A hospice program may be provided in virtually any type of living arrangement, including, but not limited to, a health care facility specifically designed for hospice care, in a hospital, in a long-term health care facility, in a developmental center, in a community residence as defined in N.J.A.C. 10:44A or 10:44B, or in a private home.

iv. Good end-of-life care for terminally ill individuals often requires the administration of care in a setting familiar to the individual. This can contribute immensely to the emotional and psychological wellbeing of the individual. Accordingly, the Division will seek to utilize generic and specialized resources towards providing appropriate hospice care to terminally ill individuals within developmental centers and community residences in New Jersey.

SUBCHAPTER 2. DEFINITIONS

10:48B-2.1 Definitions

The following words and terms, as used in this chapter, shall have the following meanings, unless the context clearly indicates otherwise:

“Advance Directive” means a written document executed in accordance with the requirements of the New Jersey Advance Directive for Health Care Act, N.J.S.A. 26:2H-53 et

seq. It is a written instruction stating the individual's general treatment philosophy and objectives, and/or the individual's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life sustaining medical treatment.

“Attending physician” means the physician selected by, or assigned to, the individual who has primary responsibility for the treatment and care of the individual.

“Bureau of Guardianship Services (BGS)” means the unit within the Division of Developmental Disabilities which has the responsibility and authority to provide guardianship of the person to individuals in need of such services (N.J.A.C. 10:45-1.2).

“Capacity” means an individual’s ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision on his or her own behalf. An individual’s decision-making capacity is evaluated relative to the demands of a particular health care decision.

“Do Not Resuscitate (DNR) Order” means a physician's written order not to attempt cardiopulmonary resuscitation in a hospital or out-of-hospital situation in the event the individual suffers cardiac or respiratory arrest.

“Emergency care” means immediate treatment provided to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

“Ethics Committee” means a multi-disciplinary standing committee, which shall be designated by the Division Director or his or her designee pursuant to N.J.A.C. 10:48B-3.1 and shall have a consultative role, when the Bureau of Guardianship Services (BGS) is the guardian, in reviewing a recommendation for a “Do Not Resuscitate Order” (DNR) or for withholding or withdrawing an individual's life-sustaining medical treatment.

“Health care facility” means a hospital, a residential health care facility or nursing home, an assisted living facility, a developmental center, or a private residential facility licensed under N.J.A.C. 10:47. Community residences licensed under N.J.A.C. 10:44A or 10:44B are not health care facilities.

“Hospice” means an approved program of care for individuals who have illnesses involving a prognosis of six months life duration or less, that is designed to allow these individuals to live as normal, comfortable, and full a life as possible until death. Hospice programs must be approved and regulated by the Department of Health and Senior Services.

“Immediate family” means spouse, children, parents, and siblings. Immediate family may also include individuals less closely related to the individual by blood or marriage, but who have been interested and involved with the individual’s welfare.

“Life sustaining medical treatment (LSMT)” means the use of any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery, or therapy that uses

mechanical or other artificial means to sustain, restore or supplant a vital bodily function and thereby increase the expected life span of the individual.

“New Jersey Protection and Advocacy, Inc. (NJP&A)” means the organization designated by the Governor to be the agency to implement, on behalf of the State of New Jersey, the Protection and Advocacy System established under the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§15041-15045.“

“Palliative care” means a holistic approach to individual care, integrating medical, psychosocial, and spiritual elements, in the presence of an incurable progressive illness that is expected to end in death. Designed to decrease the severity of pain, suffering, and other distressing symptoms, palliative care recognizes that dying is part of living. Palliative care is provided to the individual, the family, and others involved in the individual’s illness by an interdisciplinary healthcare team, including nurses, social workers, chaplains, and physicians. The expected outcome of palliative care is to enable the individual to experience an improved quality of life.

“Permanently unconscious” means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes a persistent vegetative state or irreversible coma.

“Regional Long Term Care Ethics Committee” means a multi-disciplinary body of individuals, at least two of whom have completed the training program sponsored by the Office of the Ombudsman for the Institutionalized Elderly. Regional Long Term Care Ethics Committees provide to the long-term care community expertise of multi-disciplinary members who offer case consultation and support to residents and health care professionals who are facing ethical dilemmas (N.J.A.C. 8:39-5). Regional Long Term Care Ethics Committees also provide education for residents and families, health care professionals and the local community (N.J.A.C. 8:39-13.4). Regional Long Term Care Ethics Committees provide policy development to enhance facilities' ethical decision-making.

“Supportive care plan” means a plan of care to be developed by the health care facility for each individual for whom a Do Not Resuscitate (DNR) Order is proposed. The plan is individualized to meet the individual's needs and shall consider fluid/intravenous therapies, nutrition, symptom management/medication, invasive diagnostic and therapeutic procedures including but not limited to mechanical ventilation, kidney dialysis, pulmonary, arterial or venous catheters, transfusions, laboratory, x-ray and other tests. This plan shall also include non-medical interventions that address the individual’s psychosocial and spiritual needs and may include complementary therapies, such as aromatherapy, music therapy, pet therapy, and the like.

“Terminally ill individual” means an individual receiving services from the Division, who is under medical care and has reached the terminal stage of an irreversibly fatal illness, disease or condition and the prognosis of the attending physician and at least one other

physician asserts there is no hope of cure. A continued life span of less than one year is projected.

SUBCHAPTER 3. ETHICS COMMITTEES

10:48B-3.1 Designation of Ethics Committees

(a) The Division Director or his or her designee shall identify standing Ethics Committees that shall be available for consultation to BGS whenever end-of-life decision-making issues arise, that is, requests for consent for a DNR or for withholding or withdrawing LSMT.

1. An Ethics Committee shall be asked to certify to the following:

i. Adequate knowledge, experience, and/or training regarding ethical issues pertaining to end-of-life care decision-making;

ii. Adequate knowledge, experience, and/or training regarding the nature and characteristics of individuals with developmental disabilities; and

iii. The ability to be available for case consultation in a prompt and expeditious manner proportionate to the urgency of the situation. An absolute minimum of three members of the Ethics Committee must be involved to provide consultation for any case, be it extremely urgent or less urgent in nature.

(b) The Ethics Committee may be an institutional Ethics Committee within an acute care facility where the individual is hospitalized, a Regional Long Term Care Ethics Committee, or one that has been constituted specifically to consider the ethical issues

pertaining to end-of-life care decision-making for individuals with developmental disabilities.

(c) After an Ethics Committee has been identified by the Division Director or his or her designee for end-of-life consultation, the chairperson of the Ethics Committee shall recertify annually regarding the continuing applicability of the elements contained under (b) above.

(d) Each standing Ethics Committee shall be comprised of no less than five individuals. Ideally, the membership should include:

1. A non-attending physician;
2. A non-attending nurse;
3. A social worker;
4. A member of the clergy;
5. An ethicist;
6. A lawyer; and
7. At least one member of the community interested in and experienced with individuals with developmental disabilities.

SUBCHAPTER 4. DECISION-MAKING CAPACITY

10:48B-4.1 Determination of terminally ill individuals' capacity regarding either Do Not Resuscitate (DNR) Orders or the withholding or withdrawing of life sustaining medical treatment (LSMT)

(a) It is the attending physician's role to recommend a course of treatment for a terminally ill individual, including a Do Not Resuscitate (DNR) Order and/or the withholding or withdrawing of life sustaining medical treatment (LSMT).

(b) To the extent possible, Division staff shall provide to the attending physician any information or records pertinent to the issue of whether a terminally ill individual may or may not have the capacity to make medical treatment decisions, including documents such as a previous adjudication of incapacity or a determination by the administrative head of the service unit that the individual has capacity to make medical treatment decisions.

(c) If the attending physician recommends a DNR Order or the withdrawal or withholding of LSMT, the physician must determine whether the individual has the capacity to make medical treatment decisions. In some instances the individual may not have the capacity to make major medical decisions, but may have the capacity to express some preferences about treatment options in the face of a terminal illness. The attending physician should make an effort to determine the preferences of the individual, and these should be considered in the development of the final treatment plan.

(d) The attending physician may consider information supplied by the Division staff or BGS to determine whether the terminally ill individual has the capacity to make

medical decisions. The attending physician shall be the final arbiter of the individual's capacity to make medical treatment decisions.

SUBCHAPTER 5. INDIVIDUALS WITH CAPACITY TO MAKE MEDICAL DECISIONS

10:48B-5.1 Individuals with capacity to make medical decisions

If the attending physician has determined that a terminally ill individual has capacity to make informed major medical decisions on his or her own behalf, the individual shall make decisions regarding any proposed DNR Order and/or the withholding or withdrawing of LSMT.

SUBCHAPTER 6. INDIVIDUALS WITHOUT CAPACITY TO MAKE MEDICAL TREATMENT DECISIONS FOR WHOM BGS IS NOT PROVIDING GUARDIANSHIP SERVICES

10:48B-6.1 Individuals without capacity to make medical treatment decisions for whom BGS is not providing guardianship services.

(a) If the attending physician has determined that a terminally ill individual, not receiving guardianship services from BGS, lacks the capacity to make major medical decisions, decision-making in regard to medical treatment shall proceed according to the following guidelines:

1. If the individual has a guardian other than BGS and is in a health care facility

operated or funded by the Division, a DNR Order or an order for the withholding or withdrawing of LSMT may be issued upon the recommendation of the attending physician and with the consent of the private guardian. The head of service of the Division component responsible for the individual, or his or her designee, shall provide written notice of the entry of the order to New Jersey Protection & Advocacy (NJP&A) no later than the next business day.

2. If the individual is in a health care facility not funded by the Division, decision-making regarding the issuance of a DNR Order or the withholding or withdrawing of LSMT shall be addressed in accordance with the policies, procedures, and practices of the health care facility.

3. If the attending physician determines that the individual lacks the capacity to make medical treatment decisions and the individual does not have a guardian appointed to him or her, a special medical guardian can be appointed.

SUBCHAPTER 7. INDIVIDUALS WITHOUT CAPACITY TO MAKE MEDICAL TREATMENT DECISIONS FOR WHOM BGS IS PROVIDING GUARDIANSHIP

10:48B-7.1 Individuals without capacity to make medical treatment decisions for whom BGS is providing guardianship.

If the attending physician has determined that a terminally ill individual for whom BGS is providing guardianship lacks the capacity to make medical decisions, and the physician is

recommending a DNR Order or the withholding or withdrawing of LSMT, the recommendation shall be referred to an Ethics Committee designated by the Division Director or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

10:48B-7.2 Role and functions of Ethics Committees

(a) The Chief of BGS or his or her designee shall solicit consultation from a designated Ethics Committee whenever consent for a DNR Order or for withholding or withdrawing LSMT is being requested by the attending physician. The Ethics Committee shall meet as soon as possible depending upon the urgency of the situation, but in all cases no later than two weeks from the time of the request.

(b) In an instance when the Chief of BGS or his or her designee determines that an expeditious consultation by the Ethics Committee is dictated by the emergent circumstances, for example, an issue involving a DNR request:

1. A core group consisting of at least three members of the standing committee shall convene, ideally, or communicate via conference call if necessary.
2. The committee shall consider the recommendation of the attending physician and the medical basis for such recommendation.
3. Reasonable efforts under the emergent circumstances shall be made to obtain the input of involved nurses, nurses' aides, or social workers.

4. Reasonable efforts under the emergent circumstances shall be made to involve the individual and/or family. The efforts to involve the individual and/or family shall be documented in the individual record.
5. In every instance a representative from NJP&A shall be invited to participate.
6. A recommendation by the core group shall be rendered and communicated to the Chief of BGS or his or her designee within 48 hours.

(c) The Ethics Committees shall meet not less than quarterly to review all end-of-life consultations previously done for service recipients of the Division.

10:48B-7.3 Do Not Resuscitate (DNR) Orders for individuals receiving BGS services

(a) The following procedures shall be followed when a recommendation has been made by the attending physician to execute a DNR Order for an individual for whom BGS is providing guardianship services:

1. When a recommendation is received by staff of BGS to authorize a DNR Order, the recommendations shall be referred to an Ethics Committee designated by the Division Director or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

    i. When considering a recommendation for a DNR Order, the members of the Ethics Committee shall consider:

        (1) The recommendation of the attending physician;

        (2) The diagnosis and prognosis of the individual, as confirmed by a second physician;

(3) The wishes of the individual as may have been expressed in an advance directive;

(4) The contemporaneous or previously expressed wishes of the individual, if available;

(5) The family members' perception of what might have been the individual's wishes or what is in the best interest of the individual;

(6) The likelihood of benefit if cardiopulmonary resuscitation (CPR) is instituted; and

(7) Any additional information deemed relevant to the decision.

ii. Pursuant to N.J.A.C. 10:48B-3.1(a)1iii and 7.2(b)1., at least three members of the Ethics Committee shall have considered the request for a DNR Order in order to constitute a quorum.

iii. The recommendation of the Ethics Committee shall be forwarded in writing to BGS as soon as possible, but no later than within 48 hours.

iv. If, after receiving the recommendation of the Ethics Committee, the Chief of BGS or his or her designee concurs with the recommendation for a DNR Order, the Chief or his or her designee shall prepare a certification based upon the following:

(1) The recommendation of the Ethics Committee;

(2) The recommendation of the attending physician;

(3) A summary of the individual's diagnosis and prognosis, as confirmed by a second physician;

(4) Documentation of reasonable efforts to contact immediate family members and of concurrence with the decision by those immediate family members who were contacted; and

(5) Any additional information deemed relevant to the decision.

v. Once the certification has been completed, the Chief of BGS or his or her designee shall communicate consent to the DNR Order to the attending physician and provide NJP&A with a copy of the certification no later than the next business day.

vi. If the Chief of BGS or his or her designee disagrees with, or has questions about, a recommendation of the Ethics Committee to execute a DNR Order, he or she shall reconvene the Ethics Committee for a second review in order to discuss the issues in question. If, after the second review, the Chief of BGS or his or her designee refuses to consent to the request for a DNR Order despite the recommendation of the Ethics Committee, the DNR Order shall not be written. The Chief of BGS or his or her designee shall state in writing the reasons why consent has been denied. Copies of this statement

shall be provided to the attending physician, the Ethics Committee, and NJP&A.

10:48B-7.4 Withholding or withdrawing life sustaining medical treatment (LSMT) for individuals for whom BGS is providing guardianship services.

(a) The following procedures shall be followed when a recommendation has been made by the attending physician to withhold or withdraw LSMT for an individual for whom BGS is providing guardianship services:

1. When a recommendation to authorize the withholding or withdrawal of LSMT is received by staff of BGS, the recommendation shall be referred to an Ethics Committee designated by the Division Director or his or her designee, pursuant to N.J.A.C. 10:48B-3.1, for review.

   i. In preparation for presentation of a recommendation for withholding or withdrawing LSMT to an Ethics Committee designated by the Division Director or his or her designee in accordance with N.J.A.C. 10:48B-3.1(a)1, the Chief of BGS or his or her designee shall:

      (1) Request a search of the individual's records to determine whether or not an advance directive exists;

      (2) Obtain a description of the diagnosis and prognosis of the individual which substantiates the reasonableness of withholding or withdrawing potentially LSMT based upon the finding that such

treatment would be more burdensome than beneficial, and contrary to the individual's best interest;

(3) Obtain a second opinion that confirms the individual's condition and prognosis; and

(4) Develop a profile detailing the relevant factors in a consideration to withhold or withdraw potentially LSMT including, but not limited to: permanently unconscious state, uncontrolled pain, severe and permanent physical and mental deterioration, or other similar criteria.

ii. When the information (a)1i above has been gathered, the case shall be referred to a designated Ethics Committee for review. In accordance with N.J.A.C. 10:48B-3.1(a)1 and 7.2(a), the Ethics Committee shall have a consultative role in reviewing a request to withhold or withdraw potentially LSMT.

iii. When considering a request to withhold or withdraw potentially LSMT, the members of the Ethics Committee shall consider:

(1) The recommendation of the attending physician;

(2) The diagnosis and prognosis of the individual;

(3) The wishes of the individual as may have been expressed in an advance directive;

(4) The contemporaneous wishes of the individual, if available;

(5) A second physician's confirmation of the diagnosis and prognosis;

(6) The benefits and burdens to the individual of initiating or continuing potentially LSMT;

(7) The wishes of the individual's family members;

(8) The “best interest” standard was applied with respect to withholding or withdrawing LSMT, excluding consideration of any pre-existing, non-terminal developmental disability, the benefits or burdens to third parties, or the cost of continuing medical treatment; and

(9) Any additional information deemed relevant to the decision.

iv. The Ethics Committee shall invite the Chief of BGS or his or her designee, as well as a representative of NJP&A, to attend the meeting.

v. If a majority of the members of the Ethics Committee reach consensus that it would be appropriate to withhold or withdraw potentially LSMT,

this recommendation shall be forwarded in writing to the Chief of BGS or his or her designee immediately.

vi. If a majority of the members of the Ethics Committee reach consensus that the withholding or withdrawing of LSMT would be inappropriate, or are unable to reach a consensus, this shall be reported to the Chief of BGS or his or her designee. The Chief of BGS or his or her designee will make the decision as to rendering or withholding consent.

10:48B-7.5 Procedures for rendering decision

(a) If, after receiving a recommendation of the Ethics Committee to withhold or withdraw LSMT, the Chief of BGS or his or her designee concurs with the recommendation, the Chief or his or her designee shall prepare a certification outlining the following:

1. The recommendation of the Ethics Committee;
2. The request of the attending physician;
3. A summary of the individual's diagnosis and prognosis;
4. A second opinion from another physician;
5. The disposition of the family members, if any; and
6. Any other information deemed relevant to the decision.

(b) The Chief of BGS or his or her designee shall forward the certification to NJP&A no later than the next business day. NJP&A shall notify BGS regarding any objection by way of a written communication no later than one business day after receipt of the certification. If NJP&A raises no objection to BGS's determination, the Chief of BGS or his or her designee shall authorize the withholding or withdrawing of LSMT.

(c) If the Chief of BGS or his or her designee disagrees with, or has questions about, a recommendation of the Ethics Committee to withhold or discontinue potentially LSMT, he or she shall reconvene the Ethics Committee for a second review in order to discuss the issues in question. If, after the second review, the Chief of BGS or his or her designee refuses to consent to the request to withhold or withdraw LSMT, he or she shall render such decision accordingly. The Chief of BGS or his or her designee shall state in writing the reasons why consent has been denied. Copies of this statement shall be provided to the attending physician, the Ethics Committee, and NJP&A.

SUBCHAPTER 8. PALLIATIVE CARE

10:48B-8.1 Palliative Care

(a) Palliative care services, including hospice services, may be provided for an individual with a terminal or life-threatening illness. Consideration for admission into a hospice program may require that a DNR order be in place. If so, all of the procedures for

consent to a DNR order delineated above under N.J.A.C. 10:48B-7 shall be followed prior to admission into a hospice program.

(b) Palliative care services, including hospice, may be provided in a health care facility specifically designed for hospice care, at a hospital, in a developmental center or in a community residence as defined in N.J.A.C. 10:44A or 10:44B.

Gwendolyn L. Harris, Commissioner

Department of Human Services